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## **Information systems in health care – breaking down barriers or creating more?**

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### **The contribution of information systems to breaking down barriers**

The delivery of complex services, such as healthcare, involves the co-ordination of contributions from many professionals and necessitates work across many organizational boundaries. In healthcare this means sharing information about patients between healthcare workers. Computer-based information systems have been advocated as a solution to this problem; it is very hard for healthcare workers, often spread between sites and organizations, to share bulky paper-based patient records but it is possible for them to access up-to-date electronic records of patients. In theory, therefore, moving from paper-based to electronic records should make possible the sharing of patient information and lead to the delivery of better co-ordinated care for patients.

In England at present there are two routes by which this objective is being pursued. Since 2002 there has been a national programme (NPfIT: the National Programme for IT) 'rolling-out' a suite of common IT applications to all NHS trusts in the country. Before 2002, and continuing alongside the national programme, the informatics departments of trusts have been implementing local e-patient systems to meet their specific needs.

This paper questions whether the systems that are being delivered are leading to patient information being shared between healthcare teams. We are currently engaged in the EPICOG project with two Primary Care Trusts (Northants and Walsall) to examine electronic patient systems created as part of the national programme and those that have been developed more locally. Are these systems enabling patient information to be shared across organizational boundaries, for example from GP to Hospital, from Hospital to Community Services etc?

## **NPfIT: A national IT solution**

The NPfIT programme is a 10-year, £12.6 billion project to create ‘cradle to grave’ electronic care records for all the citizens of England. It includes many different applications, for example, Choose and Book and PACS (Picture Archiving and Communication System). However, most attention has been focused on the summary care record (a summary of patient data that can be accessed across the country) and the full care record (a comprehensive patient record that can be shared across health agencies in particular regions of the country, e.g. London).

The roll-out of applications got under way in 2004 and, in May 2008 an official review of the progress of the programme published by the National Audit Office (NAO 2008a, 2008b) judged that it was four years behind schedule. Some of the applications are regarded as successful but the two core projects, the summary care record and the full care record, were beset by problems from the outset. The NAO concluded, for example, that the plans for the full care record ‘have proved impracticable’.

## **NPfIT policies, user responses and emergent needs**

In order to understand why the NPfIT programme has run into difficulties it is useful to summarise the main policies it has pursued, as listed in table one. The central policy, the top-down, roll-out of identical systems across the country, the so-called ‘one size fits all’ policy (Collins 2006), has been widely criticized as delivering systems that do not meet the varied requirements of the different kinds of trusts across the country. For example, Mental Health Trusts in London found that the record system intended for their deployment had no provision for data required by the Mental Health Act. As a result, they were allowed to implement an ‘interim’ system developed for use in mental health (Eason 2007). The emergent need is for a wider array of systems to be available that can meet the very varied needs of NHS trusts. However, these systems still have to satisfy common standards for data exchange if the objective of sharing data between trusts is to be achieved.

It is not just the overall policy that has caused problems. In the specification of technical systems and the way they have been implemented, a number of policies have been followed, some more explicitly than others, that have also created difficulties for healthcare teams. Table 1 lists the

main design and implementation policies, summarizes stakeholder responses to them and identifies ‘emergent needs’ that, so far, these systems have failed to meet.

| NPfIT Policies   | Stakeholder Responses  | Emergent Needs  |
|--|--|---|
| <b>The Strategic Approach</b>  |  |   |
| ‘One size fits all’: Everybody to use the same systems   | The standard solution does not meet our needs  | Local systems that meet common standards                                |
| <b>Technical Design and Implementation Policies</b>  |  |   |
| <b>1. Use by Whom?</b><br>Create comprehensive, analyzable and auditable patient records                                       | Data input load is heavy, highly structured and of little value to healthcare workers            | Enable healthcare workers to report patient progress in their own terms |
| <b>2. Getting benefits for healthcare</b><br>A focus on <i>access</i> to records rather than healthcare <i>process support</i> | Data record does not support specific information needs in healthcare pathways                   | Systems that support healthcare pathways                                |
| Using the system to foster ‘best practice’ in healthcare   | ‘Best practice’ is inappropriate in many situations  | Enable local development of healthcare practices                        |
| <b>3. Ownership</b><br>Create central repositories of records  | Resistance because of questions about ownership of data and controls on what can be done with it | Hold data locally and facilitate access according to need               |
| <b>3. Confidentiality and Access</b><br>Protect patient privacy by enforcing ‘role based access’                               | Often cannot access the information healthcare workers legitimately need                         | Permit local sharing of information across disciplines and roles        |

**Table 1**  
**The NPfIT Policies**

**1. Use by Whom?** A plan to create a single record raises many questions about whom the record is set up to serve and the priorities that lie behind the way it is structured. Berg et al (1998), commenting on systems in other countries, remark that comprehensive and structured records are of more value to secondary users (managers, accountants, researchers etc) than they are to operational healthcare staff. Operational staff have been largely negative about NPfIT applications because (a) inputting data to the record is often a heavy, problematic and demanding load and (b) they do not see these fragmented, standard and structured records as useful working tools for them. To be successful, the system must enable operational healthcare staff to record

working information to remind themselves about the patient and to share with colleagues. A consequence of this policy is ‘workarounds’ that turn the record into a working tool, i.e. clinical staff use free text areas of the record to store a narrative about the patient in their own words and ignore the structured parts of the record (Eason 2009).

**2. Getting benefits for healthcare** A central aim in the NPfIT is to create databases that can be accessed by legitimate users. Such systems tend to be passive holders of data and do not support the specific information needs of healthcare staff working with particular care pathways. There is a need to configure each system for this purpose. In some cases this is done explicitly and the systems ‘frame’ (Berg 1999) a process that defines the contributions of a number of healthcare staff. In theory, this should mean the information is available in an appropriate form for each step of the process. However, in many cases the system is prescriptive: it institutionalizes a view of ‘best practice’. There is evidence of circumstances where the messiness of reality means that following ‘best practice’ would be detrimental to the patient, e.g. preventing a nurse administering a drug because a doctor was not present to authorize it (Ash et al 2004).

**3. Ownership of the Record** Many healthcare staff, especially GPs, have voiced concerns about the confidentiality of patient data and have refused to release data to large databases over which they have no control. This issue raises the possibility of adopting different technical strategies, for example, storing data locally and providing access to those who need it when they need it.

**4. Confidentiality and Access** To control access to records users of NPfIT applications are issued with smart cards that define the degree of access their work role is permitted, e.g. medical staff can access medical data, administrators have more limited access. These ‘role-based access’ rules have led to teams not being able to share information. As a result some teams share the smartcard of the member of staff who has the fullest access. Formal and rigid demarcation of the access permitted to each role does not, it appears, sit easily with the demands for information sharing in a turbulent organizational environment where demarcations between work roles can become fuzzy.

**National technical system policies and local sociotechnical system requirements**

Underpinning the difficulties outlined above is the assumption that implementing these information systems is a technical design process. The agenda does not explicitly recognize that the achievement of benefits from these technical systems depends on the way they are harnessed and used by healthcare workers. The agenda needs to be expanded so that it is explicitly about the development of sociotechnical systems rather than technical ones. The emergent needs listed in the right column of table one together indicate that there is a need to balance the creation of well-governed central records with the need to create useful working tools for operational healthcare workers. Given the great variety of healthcare processes, this requirement means there is a need to allow enormous variety in the form of systems at a local level and it poses a great challenge; how to sustain an integrated national framework *and* enormous local diversity?

### **The local development of shared electronic patient records**

Early results of the EPICOG project suggest that systems designed locally may avoid some of the barriers that the national systems have encountered. They involve a close partnership between local healthcare staff, local informatics staff and suppliers, their governance is the responsibility of local clinical and informatics staff and clinically-trained staff are seconded to informatics to support, for example, the configuration of systems for local use. These procedures give hope that technical systems will be matched to local practices and requirements. Access to systems has also been developed in ways that are responsive to local circumstances, for example, patient data is held on the systems of those who generate it, i.e. in laboratories, and access by others is according to need. Role-based access rules can be overridden when there is a temporary need although the override can be audited. The development of local systems is also bringing together local organizations, for example, in primary and secondary care, that need to cooperate to share information across organizational boundaries.

### **Towards minimum critical specification**

A top-down strategy to deliver standard systems has the potential to achieve widespread sharing of patient information but, by not attending to the need to support healthcare staff dealing with very varied healthcare pathways, this technical strategy is not leading to effective adoption of systems. Early findings suggest that the local development of systems is more likely to meet local needs but systems created for entirely local needs are not going to meet the requirement to share patient information across the health service. The future development of these systems will have to find a way of meeting broad organizational needs *and* very specific and varied local needs.

Sociotechnical systems theory has historically been concerned with the problem of designing systems that facilitate the coordination of large organizations whilst simultaneously enabling discretion at a local level. Its solution is enshrined in the ‘principle of minimum critical specification’ (Cherns 1987) which states that, in the design of any system, only that which has to be specified to facilitate overall objectives should be fixed in the system; everything else should be developed locally to meet local needs. Thus trusts would select systems that complied with data standards for interoperability and would operate the systems within nationally agreed policies on patient privacy etc. Coiero (2009) echoes this approach in reflecting on the strengths and weaknesses of the ‘natural experiment’ that is the centralized ‘top down’ approach of NPfIT and the devolved ‘bottom up’ approach in the USA where local healthcare services are coming together to see what degree of cooperation is possible. He concludes that a ‘middle out’ strategy is needed in which government establishes a minimum set of policies for healthcare informatics and a standards development process as a framework within which each healthcare agency can then select and develop systems to serve their local needs.

A strategy of this kind may well serve to prevent the experience that so many healthcare workers have of the NPfIT, of systems that do little to help and sometimes much to hinder their day-to-day work. However, such a strategy needs to be recognized for what it is. It is a policy for the creation of a technical architecture that is a necessary but not sufficient condition for electronic patient information to be widely and usefully shared. It leaves at a local level the need to specify and configure systems to meet local needs and the need for local organizational structures and working practices to evolve to take advantage of the new opportunities that shared information may offer.

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